



NIKAVIKA
SISTERHOOD

engage. enlighten. empower.

Inclusion Coaching Packet



Cassidy (center) high-fives a few girls at our first Inclusion coaching event, April 2018

✘ Activity #1 | Cassidy's Journey ✘

Read about Cassidy below and as you do, underline or highlight what you feel are the most compelling and inspiring aspects of her journey.



Sam Drazin and Cassidy Nicholas

In April of 2018, Cassidy Nicholas joined NikaVika SisterHood for our very first inclusion coaching event at the Milton Public Library. This inspiring event was led by Sam Drazin, a teacher, educator, motivational speaker and the founder of Changing Perspectives based out of Bradbury, Vermont. Sam's magical coaching session centered around choosing kind, empathy and inclusion, drawing from R.J. Palacio's equally magical novel, *Wonder*.

Just like Cassidy, and *Wonder's* magnetic character Auggie Pullman, Sam was born with Treacher Collins Syndrome. During his coaching session, Sam drew parallels between his life and that of Auggie's through thought-provoking anecdotes,

engaging turn and talks, and realistic role-playing among the younger girls. Both informative and uplifting, Sam's coaching resonated with a wide range of our members.

To learn more about Sam and his inspiring work please visit <http://cpne.org> and check our online calendar often to see when he'll be coaching with us in 2019.

Now let's get back to our very own "Wonder Girl." Cassidy Claire Nicholas was born in August 2012 with Treacher Collins Syndrome, a rare genetic disorder that was a result of a spontaneous mutation of the fifth chromosome causing malformation of her facial bones. Cassidy has a severe case of TCS. Neither her parents nor her team of doctors knew that she was afflicted with this syndrome before her birth.



Cassidy's First Birthday, August, 2013

Cassidy was immediately intubated after birth as she was born with no viable airway. A tracheostomy was performed when she was just two days old. Cassidy with born with several extreme conditions: 1) choanal atresia, so there was no passage between her nose and mouth 2) micrognathia, meaning that her jaw was underdeveloped, lacking hinges and growth sacs; 3) mylar hypoplasia: she lacks cheek bones.

In addition to these abnormalities, Cassidy also has bilateral microtia; which means that she was born without ear canals, ear drums or ear bones. Her earlobes are not completely developed and she is also missing an inner ear canal on each side. Fortunately, her cochlear nerves remain intact so she is able to hear with the assistance of a soft band, bone-anchored hearing aid. Additionally, Cassidy was born with a cleft soft palate.

After a six week stay in the NICU at Tufts Medical Center, Cassidy went home with her parents, Eva and Jeremy. She has already undergone many surgeries over the past 6 years and will face many more for years to come. Despite all of her physical shortcomings, Cassidy is an engaging, loveable and inspiring little girl.

In July of 2018, Cassidy's Craniofacial Surgeons began the process of reconstructing her tiny jaw since it lacks hinges on both sides which is preventing its growth. Extracting rib bone and cartilage from Cassidy, her doctors were able to sculpt hinges for her. They also implanted plates in her face so that the rib bone will rest against them and hopefully push her jaw forward. Future successful surgeries will result in her jaw bone beginning to grow and the removal of her trach.

Because of the generosity of those who have donated in past years, Cassidy and her family were able to attend the 2017 Childrens' Craniofacial Association annual retreat held in Virginia where Cassidy was able to meet many children who are like her.

Always looking ahead to the next surgeries that will improve their daughter's life, Eva and Jeremy have their sights set on Medpor ear surgery for Cassidy. Because of the significant amount of rib bone and cartilage that will be used for her jaw surgery, there will not be enough natural material to construct prosthetic ears for her. Even with insurance, Medpor surgery can cost upwards of \$50,000 per ear. More about fundraising efforts for Cassidy will be provided in Activity #6.



The Nicholas Family, 2018 Summer Vacation in Maine



Cassidy's Advertising Debut, May 2018

✦ Activity #2 | Tuft's Floating Hospital for Children ✦

View the video below with Cassidy, her parents, and her doctors from Tufts Floating Hospital for Children. It's only about 2 minutes long, but you may want to replay it a few times when working on the questions below. [Click here to watch the video.](#)

How does Dr. Scott describe Treacher Collins Syndrome (TCS)?

What are the main struggles faced by someone born with TCS?

What three adjectives would you choose to describe Cassidy?

What do you feel would be the most difficult challenge(s) if you had TCS?



Annika, Cassidy and Casey at our 2018 SisterHood SpotLight

✦ Activity #3 | Cassidy's Crusaders ✦

Pick two Posts and two Videos from Cassidy's Facebook Page. Choose one from earlier in her childhood / journey and then one that's more recent. [Click here for Cassidy's Facebook page.](#) Describe the posts and videos in your own words here:

Post 1 _____

Post 2 _____

Video 1 _____

Video 2 _____

If you chose a "serious" post or video, about Cassidy's journey with TCS, what is the most remarkable aspect of her progress and what inspires you the most about her?

If you chose a more "playful" post or video, what did you enjoy the most about Cassidy's personality and talents? One of her songs? A new hairstyle or outfit?

Cassidy is clearly a confident young girl who has a positive, uplifting personality and has set some big goals for herself. What do you think helps her to feel so confident and empowered?

If you have a chance to meet Cassidy, what will you ask her or share with her?

And if you had to pick one aspect about Cassidy's journey or personality that inspires you the most, what would that be?

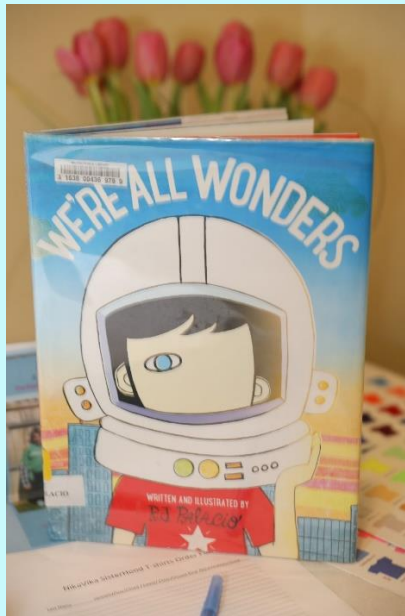
If you'd like to share any of your journaling with Cassidy and/or with NikaVika SisterHood, you can do that through a.....

- ✘ **Facebook Post on NikaVika SisterHood or Cassidy's Crusaders:** email it to us for "safe posting" including your first name, your age, and your town.

- ✘ **Letter, Picture or Card for Cassidy:** we will send fun SisterHood Surprises all year to Cassidy's. Email us for details.

- ✘ **SisterHood SpotLight:** meet Cassidy at one of our Inclusion coaching events this year where you will participate in a group interview for our 2019 SpotLight with Cassidy! (And view our 2018 interview on [YouTube!](#))

- ✘ **Blog Post:** to be shared on www.nikavikasisterhood.com within our future Blog, including inspirational posts from our SisterHood members!



The Younger Version of "Wonder"

✧ Activity 4 | Sam Drazin's Journaling Prompts ✧

Take your time reflecting about what you have learned and if you haven't read the book and seen the movie Wonder, definitely do that! Also ask teachers, librarians or gurus at your favorite book store for suggestions on books about inclusion and empathy. Some of our favorites are: Braced by Alyson Gerber, Blubber by Judy Blume and Fish in a Tree by Linda Mullaly Hunt. But we will post more soon!

What does it mean to be different?

How would you describe visible vs. invisible differences?

Have you ever judged someone purely based on the way they look?

What makes you different from others?

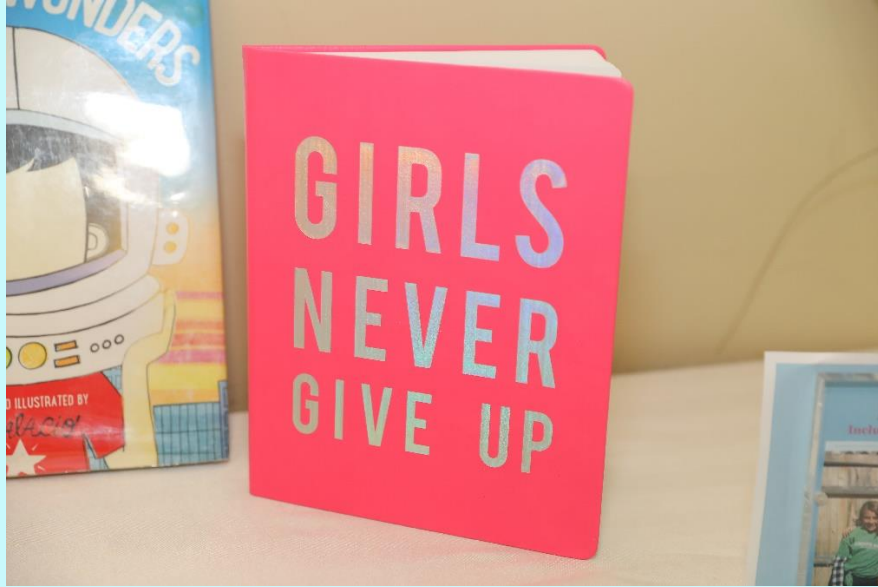
Is being different a good thing? A bad thing?

What is your definition of empathy?

What is inclusion?

What needs to change in our society to be more inclusive of all people?

Instead of ignoring each other because of our differences, we should recognize people in positive ways for what makes them different. Consider going out of your to recognize someone's differences in a positive and encouraging way, and journal about it here, or draw a picture or comic strip that illustrates your mindset change!



Let's Get This Inspiration Started!

✘ Activity #5 | Quotes To Live By ✘

Read over the quotes below and then consider writing one of your own. Maybe it's more of a maxim instead of a quote...like those that were discussed in Wonder with Mr. Brown's class.

Treat others the way you want to be treated

Don't judge a book by its cover

"When given the choice between being right or being kind, choose kind." – Dr. Wayne Dyer

**"Kind words do not cost much. Yet they accomplish much."
– Blaise Pascal**

Write your own quote or maxim here (and share with us if you'd like!)



Katie, Annika + Jenna join Cassidy at her 2018 Run/Walk

✘ Activity #6 | Cassidy's Run for the Kids ✘

Consider participating in this year's event on Sunday June 2, 2019! For the past 6 years, Cassidy's Run for the Kids, a 5K run and walk, has been held near Cassidy's home in Haverhill, MA. It's a lot of fun and 100% of the profits go directly to Cassidy and the Nicholas family to the offset costs of her future surgeries. In addition to those mentioned above, additional surgeries will include: construction of prosthetic cheekbones, ears and restructuring Cassidy's nose and eyelids. With your help, Cassidy can look forward to living a life with a normal face. [Click here to learn more about this inspiring event and to register, donate or sponsor.](#)

